Benefit Finding in Children with Advanced Cancer and their Parents

Honors Research Thesis

Presented in partial fulfillment of the requirements for graduation *with honors research distinction* in Psychology in the undergraduate colleges of The Ohio State University

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April 2021

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Abstract

Background: Although childhood cancer causes significant stress, most survivors are resilient and do not exhibit severe or lasting psychopathology. Research is limited, but some survivors may even report benefit finding or positive outcomes following this stressful life event. However, considerably less research has included families of children who are unlikely to survive their illness. Thus, this study investigated benefit finding among parents and their children with advanced cancer, as well as associated demographic and medical factors.

Methods: Families (n = 57) of children with advanced cancer (ages 5-25) were recruited from a large pediatric hospital. Advanced cancer was defined as relapsed or refractory disease, a prognosis of <60%, or referral to end of life care. Participants completed a demographic survey and the Benefit Finding Scale at enrollment.

Results: Children, mothers, and fathers reported moderate to high benefit finding scores. Correlations between family members were weak and non-significant. Children reported significantly higher benefit finding than fathers. Demographic and medical factors were not associated with benefit finding in children, mothers, or fathers.

Conclusions: Families of children with advanced cancer reported moderate to high benefit finding regardless of background or medical factors. Children also identified benefits of their cancer experience independent of the experiences of their mothers and fathers. Larger studies should continue to examine factors associated with both positive and negative outcomes in the context of childhood cancer to inform more effective interventions.

Childhood cancer is the number one cause of death by disease for children ages 1-19 in the United States (Siegel et al., 2019). Over 20,000 children are newly diagnosed and about 1,800 die from cancer each year. As treatment has improved, survival rates have also increased, with 83.4% of children now surviving cancer for at least 5 years (Siegel et al., 2019). The most common types of cancers in children under age 19 include leukemias (28%) and brain and nervous system cancers (26%). The most common diagnoses in adolescents ages 15-19 include brain and nervous system cancers (21%) and lymphomas (20%; Siegel et al., 2019). Treatment for each type of cancer varies, but most children receive multi-modal therapies, such as surgery, chemotherapy, radiation, and/or stem cell transplant. Depending on the diagnosis, treatment typically lasts from several months to three years and causes significant acute and chronic side effects, such as nausea, vomiting, hair loss, and fatigue.

Cancer is a complex disease, causing significant stress in the lives of both the patient and their family as they cope with its challenges (Tedschi & Calhoun, 2004). Common stressors include changes in daily/role functioning, caregiving demands, and communicating about cancer. Mothers and fathers of children with cancer report caregiving as their most frequent stressor, partly due to the uncontrollability of helping their child feel better and uncertainty about their child's survival (Rodriguez et al., 2011). Children with cancer face difficult treatments, painful procedures, and disruptions in their school and social activities. The most frequently reported stressor among children is not being able to do the things they were able to do before having cancer (Rodriguez et al., 2011). Some families exhibit ongoing challenges following a diagnosis, such as feeling disconnected from each other, being less involved in family activities, or failing to adjust family roles in times of stress (Long & Marsland, 2011).

Recent systematic reviews and meta-analyses indicate that parents are at risk for psychological distress in response to their child's cancer diagnosis (Clark et al., 2009; Klassen et al., 2007; Pai et al., 2007; Vrijmoet-Wiersma et al., 2008). Symptoms of anxiety and depression are reportedly highest after diagnosis but tend to decrease over time (Vrijmoet-Wiersma et al., 2008; Clark et al., 2009; Klassen et al., 2007; Pai et al., 2007). Among parents of children currently receiving cancer treatment, mothers generally report more distress and more stressors than fathers (Vrijmoet-Wiersma et al., 2008; Clark et al., 2009; Pai et al., 2007; Rodriguez et al., 2011). However, some studies have found that fathers have higher levels of distress than mothers, particularly if they are the primary caregiver (Rosenberg et al., 2012; Long & Marsland, 2011). When compared to parents without a child with cancer, levels of anxiety and depression in parents of children with cancer are higher (Vrijmoet-Wiersma et al., 2008). Some parents who report symptoms of anxiety or depression are at an increased risk for post-traumatic stress symptoms (PTSS) and/or maintaining depressive symptoms over time (Vrijmoet-Wiersma et al., 2008; Clark et al., 2009; Klassen et al., 2007; Pai et al., 2007). When treatment is unsuccessful, parents of children at the end of life and bereaved parents have higher rates of PTSS and poorer adjustment when compared to parents of survivors (Rosenberg et al., 2012).

Similar to parents, children diagnosed with cancer may experience psychological distress in response to their cancer experience. Many studies have found that children with cancer, or adult survivors of pediatric cancer, have worse quality of life and higher levels of distress (e.g., PTSS, anxiety, and depression) than healthy peers (Zeltzer et al., 2009, Compas et al., 2014, Portteus et al., 2006), while other studies have found no significant differences (Pinquart & Shen, 2011, Bennett, 1994, Kersun, 2009). Children with leukemia or cancer of the central nervous system (CNS) are at higher risk for psychosocial difficulties (Krull et al., 2008; Wulff-Burchfield

et al., 2019; Zeltzer et al., 2009). Generally, these children receive more neurotoxic treatments that increase their risk for cognitive impairments, such as decreased attention, poor memory, and declines in global intelligence, which can then have downstream effects on social and emotional functioning (Zeltzer et al., 2009; Krull et al., 2008; Wulff-Burchfield et al., 2019).

Although a subset of both parents and children with cancer struggle to cope with their diagnosis, most individuals are resilient and do not exhibit severe or lasting psychological distress (Stuber & Strom, 2012). Increasingly, positive psychology approaches have shifted away from focusing on psychological impairment, as has historically been done, instead aiming to understand competencies and adaptive functioning (Gable & Haidt, 2005). Benefit finding, the idea that someone can find positive outcomes from a stressful life event, is one such construct that has received more recent attention (Helgeson et al., 2006). Examples of benefit finding include a person with cancer realizing that they make more time for their relationships, or noticing the small things in life more often than before the stressful event.

Benefit finding has been conceptualized in various ways. Posttraumatic growth and benefit finding are often considered the same construct, because they both describe a positive change or experience following a negative life event (Phipps et al., 2007). Despite their similarities, there are important theoretical distinctions between the two (Phipps et al., 2007). Benefit finding does not require an experience to be traumatic, whereas posttraumatic growth does. Benefit finding can occur regardless of whether the individual identifies a fundamental shift in their perspective on life. It can also occur in the midst a stressful life event, whereas posttraumatic growth takes time to develop after the conclusion of the trauma (Phipps et al., 2007, Gardner et al., 2017). Some research has examined associations between child benefit finding and parent posttraumatic growth, finding that the two are positively related, but to our

knowledge, research has yet to examine associations between child and parent benefit finding (Michel et al., 2009). Given the limited research on benefit finding in pediatric cancer and recent evidence suggesting more overlap between the two constructs, literature about both posttraumatic growth and benefit finding are included (Applebaum et al., 2020).

Demographic factors have been associated with benefit finding and posttraumatic growth among both adults and children with cancer. Younger adults tend to exhibit more posttraumatic growth and benefit finding from a cancer diagnosis than older adults, and the same was found in a longitudinal study of adolescent and young adults who were undergoing cancer treatment (Helgeson et al., 2006; Husson et el., 2017). However, research with children and adolescents found that older survivors reported more benefit and growth, suggesting a curvilinear association with age. Children first diagnosed with cancer above the age of 5 years old reported more posttraumatic growth than children younger than 5 years old. This could be explained by older survivors' ablility to remember and understand their cancer experience, and then further reflect and incorporate that information into their beliefs about their life (Barakat et al., 2005). However, it is important to note that some studies have not found associations between age and benefit finding (Phipps et al., 2007).

Biological sex has also been investigated in relation to benefit finding with mixed results. Among adults, women generally and women with cancer report more benefit finding and posttraumatic growth than men (Helgeson et al., 2006; Barakat et al., 2005; Tomich & Helgeson, 2004; Husson et al., 2017). This may be explained by the tendency for women to be more emotion-focused when processing traumatic experiences and thus able to identify positive outcomes (Stanton et al., 2006). The data are mixed on sex differences in benefit finding among children with cancer. Some studies have found similar levels of benefit finding in females

compared to males (Phipps et al., 2007; Michel et al., 2010), while a study of 15-39 year old survivors of childhood cancer found that women reported more posttraumatic growth than men (Husson et al., 2017).

Other demographic factors, like race and income, have been examined less frequently in relation to benefit finding. In the adult cancer literature, BIPOC (Black, Indigenous, people of color) individuals have shown higher levels of benefit finding when compared to white individuals (Helgeson et al., 2006). Other studies have found no differences in levels of posttraumatic growth based on race (Cordova et al., 2001, Husson et al., 2017). Children with cancer have replicated trends of BIPOC individuals showing more benefit finding than white individuals (Phipps et al., 2007). Associations between income and benefit finding have also been mixed, with some research finding no correlation between income and benefit finding, and others showing that as income decreases, benefit finding increases (Barakat et al., 2006, Cordova et al., 2001, Lechner et al., 2003).

Time since diagnosis was found to positively correlate with benefit finding in a study with adult breast cancer survivors (Cordova et al., 2001), but other studies have found no association between time since diagnosis and posttraumatic growth (Stanton et al., 2006; Pakenham & Cox, 2009). These differences in findings may be explained by the fact that posttraumatic growth often takes time to develop and includes various stages an individual progresses through, such as rumination and cognitive restructuring, before growth from an adverse life event. Thus, it is necessary to consider how the timeframe of each study may affect the strength of correlations between time since diagnosis and benefit finding (Tedeschi et al., 1998). For example, Stanton and colleagues found that posttraumatic growth was reported most frequently at one to two years after a cancer diagnosis (Stanton et al., 2006).

Other medical factors, such as diagnosis, are equally important to consider, as children with CNS tumors and leukemia are more likely to experience negative effects on cognitive functioning (Compas et al., 2017). Surgery, radiation, and chemotherapy, when directed to the CNS, can damage tissue and can result in cognitive and psychosocial difficulties in survivors (Marusaki et al., 2017). One study found that survivors of leukemia and CNS cancers experienced more benefit finding when compared to other solid tumors, however children with CNS cancer had lower rates of enrollment and study completion (Michel et al., 2010). The authors proposed that individuals that chose not to participate or did not complete the study may have declined due to cognitive difficulties from their treatment (Michel et al., 2010). Thus far, there is little literature investigating the association between diagnosis type and benefit finding.

Positive psychology remains a fairly new field (Helgeson et al., 2006), and to date, benefit finding, posttraumatic growth, and resilience, are often considered equivocal, rather than recognizing a distinction between these constructs. Most research has examined benefit finding in adults with cancer, while few studies have included children with cancer. Of these studies, most occur during survivorship or have a heterogenous sample, including both children who were newly diagnosed with cancer and children who are many years past their diagnosis (Klassen et al., 2007). To our knowledge, no studies have included children with advanced cancer, because they are considered a vulnerable population and might not wish to participate in research. However, such research has great potential to further understand the experiences of individuals near the end of their life and inform interventions that prevent or reduce suffering (Hinds et al., 2004).

Thus, this study aimed to characterize benefit finding among children with advanced cancer and their parents and to identify individual and medical factors related to benefit finding.

This study fills a gap in psycho-oncology research by examining benefit finding in a population that is currently receiving treatment, investigating benefit finding in children, and exploring the association between parent and child benefit finding, all of which have received limited attention. We expected that child and parent benefit finding would be positively correlated, but that parents would have significantly greater benefit finding than children. We also expected that older age, female sex, longer time since diagnosis, and a diagnosis other than CNS tumor or leukemia would be related to higher levels of benefit finding in children with advanced cancer.

Methods

Data for this paper were part of a larger study examining quality of life and decision making in children with advanced cancer and their parents. The larger study involved assessments and interviews with families at enrollment (T1), 6 months (T2), and 12 months (T3), as well as monthly, brief online surveys regarding the child's symptoms and quality of life.

Participants

Families were eligible for the study if the child had advanced cancer, were 5-25 years old, had at least one parent who spoke English, and lived within 140 miles of Nationwide Children's Hospital. Advanced cancer was defined as any relapsed or refractory disease, physician estimated survival <60%, or referral to end-of-life care. Children with significant developmental disabilities were not eligible. Mothers, fathers, and the child with cancer were recruited for the study.

Sample Charactersitics

Of 96 families approached to participate, 57 (59.3%) enrolled in the study, resulting in 45 mothers, 24 fathers, and 36 children who were above age 8 and able to provide self-report. Data from one mother were dropped, because she did not complete the Benefit Finding Scale. Detailed

demographic characteristics are presented in Table 1. Of all 57 children in the study, the average age at T1 was 13.3 years (*SD* = 4.6), and most were male (*N* = 39; 68.4%), White (*N* = 48; 84.2%), and/or non-Hispanic (*N* = 57, 100%). The most common diagnosis was brain tumors or other solid tumors (*N* = 35; 61.4%), with an average age at diagnosis of 10.5 years old (*SD* = 5.3). Of the 36 children who provided self-report, the average age was 14.9 years old (*SD* = 3.4). The average age of mothers was 42 years old (*SD* = 6.01), and most were White (*N* = 38; 86.4%), and/or non-Hispanic (*N* = 43; 97.3%). The average age of fathers was 43.8 years old (*SD* = 6.22), and most were White (*N* = 19; 79.2%), and/or non-Hispanic (*N* = 24, 100%).

Procedures

Eligible families were identified through the palliative care or oncology teams, as well as review of inpatient records. The study coordinator contacted families in the clinic, hospital, or via phone to introduce the study and assess interest in participation. Following informed consent/assent, study staff scheduled a time to conduct an initial assessment with parents and children in the hospital or home. Participants above the age of 8 completed assessments if they were alert and able to provide self-report. If the child was below the age of 8, only parent report was obtained. Research assistants conducted each assessment with participants one on one, either virtually or in person depending on their enrollment during the COVID-19 pandemic, to ensure confidentiality and provide any assistance if needed. Families were compensated $40 for the initial home/hospital visit and $5 for monthly measurements.

Measures

Demographic Questionnaire. A demographic form was created by the research team to collect family background information such as age, date of birth, education level, race, household income, and religion.

The Benefit Finding Scale (BFS) (Antoni et al., 2001). The BFS was used to measure benefit finding in mothers and fathers with 17 items that ask about personal growth, relationship improvement, and purpose in life. Sample items include, "having a child with cancer has led me to be more accepting of things" or "having a child with cancer has contributed more to my overall emotional and spiritual growth." The items were rated on a scale from 1 'not at all' to 5 'extremely,' resulting in an average item score. Evidence supports internal reliability and convergent and discriminant validity (Antoni et al., 2001). Construct validity was confirmed by two different studies (Pascoe and Edvardsson, 2015; Li et al., 2017). Internal consistency was acceptable for both mothers (α=.93) and fathers in this sample (α=.94). The BFS was administered to parents at T1, T2, and T3.

The Benefit Finding Scale for Children (BFSC). This instrument assessed benefit finding in children using 10 items (Phipps et al., 2007). The BFSC provides statements like "having had my illness has helped me become a stronger person" or "having had my illness has helped me to be more patient." Items are rated on a scale of 0 'not at all true for me' to 5 'very true for me,' resulting in an average item score. The BFSC has excellent reliability (Michel et al., 2010; Phipps et al., 2007) and was administered to children at T1, T2, and T3. Internal consistency was acceptable in this sample (α=.85).

Electronic Medical Records. Medical records were reviewed by research staff using a structured form to collect data about diagnosis type, time since diagnosis, and treatment type.

Analysis Plan

Descriptive statistics were calculated for variables of interest. Average item scores were calculated only when at least 80% of items on the measure were completed by participants. Associations between parent and child benefit finding were examined using Pearson correlations

(α = .05, two-way), and paired *t*-tests (α = .05, two-way) were used to examine differences between informants within families (i.e., mother-child, father-child, mother-father). Associations between medical/demographic factors and benefit finding in both parents and children were also examined using Pearson correlations or *t*-tests (α = .05, two-way) as appropriate. Cohen's *d* effect sizes were calculated for paired comparisions. To determine the relative contributions of significant demographic or medical factors to child and parent benefit finding, hierarchical regressions were planned. Using Gpower, the sample of 44 mothers provided power (.66 -.82) to detect medium effects for *t*-tests (*d* = .50) and correlations (*r* = .30) (Faul et al., 2007). The sample of 24 fathers and 36 children provided power (.83-.97) to detect large effects for *t*-tests (*d* = .80) and correlations (*r* = .50), respectively.

Results

Benefit Finding in Mothers, Fathers, and Children

The average benefit finding score for children was 3.82 (*SD* = 0.80), indicating moderate to high benefit finding on a 5-point scale. The average benefit finding score for mothers and fathers was 3.86 (*SD* = 0.81) and 3.17 (*SD* = 0.84), respectively, on a 5-point scale. Correlations can be found in Table 2. Child benefit finding scores were not significantly correlated with mother scores, $r(27) = .22$, $p = .28$, or father scores, $r(15) = .21$, $p = .46$. Mother and father benefit finding scores were also not significantly correlated, $r(15) = .44$, $p = .10$. Paired sample *t*-tests revealed there were no significant differences between mother benefit finding scores ($M = 3.58$, $SD = 0.87$) and child benefit finding scores ($M = 3.79$, $SD = 0.79$), $t(26) = 1.05$, $p = 0.30$; $d = 0.25$. However, father benefit finding scores ($M = 3.27$, $SD = 0.91$) were significantly lower than child scores ($M = 4.16$, $SD = 0.63$), $t(14) = -3.48$, $p = .004$; $d = 1.14$. Mother ($M = 3.55$, *SD*

= 0.83) and father (*M* = 3.18, *SD* = 0.88) benefit finding scores did not differ, *t*(14) = 1.58, *p* = .14; *d* = 0.43.

Associations between Benefit Finding, Demographic Characteristics, and Medical Factors

There were no significant differences in male (*M* = 3.78, *SD* = .69) and female (*M* = 3.91, *SD* = 1.02) benefit finding scores; *t*(34) = -0.418, *p* = .68; *d* = 0.13. Benefit finding scores did not differ between White (*M* = 3.83, *SD* = 0.82) and BIPOC children (*M* = 3.79, *SD* = 0.72); *t*(34) = 0.096, *p* = .74; *d* = 0.04. Child scores were not significantly correlated with age at enrollment, *r*(36) = .26, *p* = .13, child age at diagnosis, *r*(36) = .19, *p* = .28, or time since diagnosis, *r*(36) = .001, *p* = .997. Due to small sample sizes, leukemia and brain tumor diagnoses were collapsed into one group and lymphoma and other solid tumors were collapsed into a second group. There were no significant differences in benefit finding for children diagnosed with leukemia/brain tumors (*M* = 3.95, *SD* = 0.69) or lymphoma/other solid tumors (*M* = 3.75, *SD* = 0.86); *t*(34) = 0.863, *p* = .24; *d* = 0.26.

Parent age was unrelated to mother, *r*(44) = -.01, *p* = .93, and father benefit finding scores, *r*(24) = -.17, *p* = .44. Level of education was also not correlated with mother benefit finding scores, r(43) = .04, *p* = .78, or father benefit finding scores, *r*(24) = .03, *p* = .89. With regards to child medical factors, time since diagnosis and age of child at diagnosis were not significantly correlated with mother benefit finding, *r*(44) = -.17, *p* = .28 and *r*(44) = .11, *p* = .95, or father benefit finding *r*(24) = -.02, *p* = .93 and *r*(24) = -.17, *p* = .42, respectively. Benefit finding scores did not significantly differ between White mothers (*M* = 3.64, *SD* = .80) and BIPOC mothers (*M* = 3.91); *t*(42) = -0.794, *p* = .73; *d* = 0.33. Sample size restraints limited comparisons based on race of fathers.

Due to the lack of significant associations between benefit finding and other demographic and medical factors, planned multi-variate models examining their relative contribution to benefit finding were not conducted.

Discussion

Limited research has examined benefit finding in adults or children with advanced cancer. Using standardized measures to assess benefit finding in both parents and children, this study is one of the first to explore benefit finding among multiple family members, as well as potentially related demographic and medical factors, in the context of the child's advanced disease. The results of this study show that despite having an unlikely prospect of cure, both the children with cancer and their parents found moderate to high levels of benefit finding from the cancer experience. In general, family members were able to report benefits independent of one another, and there were few demographic or medical factors associated with variability in benefit finding.

Children with advanced cancer in the current study had moderate to high levels of bebenfit finding, which was higher than in other populations of children with cancer (Phipps et al., 2007; Michel et al., 2009). This could be due to the curvilinear relationship between stress and benefit finding, which proposes that too little stress will not result in benefit finding, while benefit finding is unable to occur if stress is too high (Lechner et al., 2003; Cordova et al., 2001; Helgeson et al. 2006). Given that most children in the sample were not imminently at the end of life, it is possible that they had sufficient, but not overwhelming, stress to account for this effect.

Parent benefit finding scores were also moderate to high and comparable to scores in adults with cancer (Lechner et al., 2003; Applebaum et al., 2020; Llewellyn et al. 2013). When compared to child benefit finding scores, father benefit finding scores were significantly lower,

but mother scores were not significanly different from those of children or fathers. Fathers may not process the trauma of their child's cancer diagnoses in a way that results in the same levels of benefit finding as children who have cancer; however, future work is still needed to better understand father-child dyads in pediatric oncology (Stanton et al., 2006). Although fathers had significantly lower benefit finding scores compared to their children, it should be noted that they did still find moderate levels of benefit finding. Our data also suggest that child and parent benefit finding may be relatively independent of one another. Benefit finding between father and child, mother and child, and mother and father were not significantly correlated, as was also found in a study of survivors of childhood cancer (Michel et al., 2009). However, the moderately sized correlations between mothers and fathers in the current study suggest the possibility of associations and need for additional research.

Unlike many other studies investigating benefit finding in individuals with cancer, we did not find any significant associations with demographic variables. Most of the literature suggests a curvilinear relationship between age and benefit finding, with very young children and older adults finding less benefit than middle aged teenagers and adults (Helgeson et al., 2006; Husson et el., 2017; Linley & Joseph, 2004). Our sample did not exhibit any significant correlations between age at enrollment and benefit finding in both parents and children, as has been previously found in the child literature (Phipps et al., 2007). However, correlations between child age and benefit finding were weak to moderate sized (r = .26) and in the expected direction. Child age at diagnosis was also not significantly correlated with benefit finding, contrasting other studies that have found that children who are younger at diagnosis find less benefit than children who are older (Michel et al., 2009; Phipps et al., 2007; Barakat et al., 2005). This could be a result of only children ages 8 and older completing self-reports of benefit finding.

Time since diagnosis also did not exhibit any significant associations with benefit finding, contrasting other studies that found a negative association with time since diagnosis (Phipps et al., 2007; Michel et al. 2009). This is likely because both of these studies recruited cancer survivors who were many years past their diagnosis. The literature suggests that once a person is no longer receiving treatment for a long period of time, benefit finding scores decrease (Phipps et al., 2007). However, because our sample of children with advanced cancer were still undergoing treatment during the study, they may have been unlikely to show the same decline in benefit finding (Phipps et al., 2007).

Other demographic characteristics such as sex, family income, race, parent education, and cancer type did not reveal any significant associations with mother, father, or child benefit finding. With regards to sex differences, male and female children did not have significantly different benefit finding scores, which has also been found in previous literature (Phipps et al., 2007; Michel et al., 2010; Lechner et al., 2003). There were also no significant differences between mothers and fathers, contrasting the literature that supports sex differences in benefit finding (Helgeson et al., 2006; Barakat et al., 2005; Tomich & Helgeson, 2004; Husson et al., 2017). However, our study had a small number of parent dyads, which restricted our ability to compare scores between mothers and fathers.

Previous literature is mixed regarding associations between income and benefit finding with some studies finding no associations and others finding a negative association (Lechner et al., 2003; Linley & Joseph, 2004; Tomic & Helgeson, 2004). Although our study did not find any significant correlations with family income, moderately sized correlations among fathers (r = -.36) suggest futher exploration is needed in larger samples. In addition, parent education was also not a significant predictor of benefit finding, but small correlations with mothers' education

level (r = -.26) are consistent with previous work. Specifically, research suggests that individuals with lower education and income are more experienced at finding positive aspects out of negative life events (Phipps et al., 2007). Because life threatening cancer is such an prominent stressor however, this stress could have possibly overshadowed any effects of other demographic variables on benefit finding.

Child benefit finding was not significantly different when compared between diagnostic groups, contrasting research showing that children with leukemia find more benefit compared to other diagnosis groups (Michel et al., 2009). However, previous work examined children who were years past their cancer diagnosis. Leukemia often requires much longer treatment than solid tumors and CNS tumors, suggesting that children who had leukemia found more benefits from their cancer experience because it affected their life differently than other cancers. In this study, all participants were still receiving some form of treatment, so differences in benefit finding scores across diagnostic groups may not have been identified. Of note, we were limited in our comparison of treatments groups, as only two children with CNS tumors were able to complete the benefit finding measure. The lack of any significant associations suggests that benefit finding may occur in children and parents regardless of these demographic or medical factors.

There are a variety of limitations that should be considered when reviewing the conclusions of this study. Restrictions due to the COVID-19 pandemic disrupted recruitment at the hospital and clinics, as well as in-person data collection for these immune compromised patients. Despite attempts to shift to remote methods, our sample size was smaller than anticipated, and participation of each family member varied from family to family. Twenty-four fathers out of 57 families participated in the study, which restricted the ability to examine associations with child and mother benefit finding, as well as differences based on various

background factors for fathers. The overall sample size also led to a smaller number of children with brain tumors who were able to complete measures. Brian tumors are more likely to be diagnosed in young children (under age 5), which limited enrollment and the ability to compare benefit finding across diagnosis groups. The sample was also predominantly White and non-Hispanic, which limits generalizability to other racial groups. The sample was recruited from only one site, and further studies should include multiple institutions to increase diversity and generalizability to other regions. Given the cross-sectional design of this work, studies should also investigate benefit finding at multiple points over a longer period of time to understand how benefit finding develops and evolves for both children and parents. Lastly, future research should investigate how benefit finding could serve as a protective factor against distress and other negative outcomes.

Despite these limitations, this study is one of the first to examine benefit finding among children with advanced cancer and explore associations between child and parent benefit finding. Our results show that children with advanced disease can still find benefits from their cancer experience, and demographic and medical factors do not necessarily determine who is more or less likely to find benefits. With this information, clinicians and parents may be reassured that many children with advanced cancer may exhibit resilience in spite of significant adversity. Such adversity may bring into sharper focus the importance of close relationships, positive experiences, and finding a silver lining in midst of unimaginable challenges. If family members are receptive, clinicians should continue to encourage finding meaning from a cancer diagnosis, which has been shown to be valuable in both children, parents, and adults at the end of life (Schaefer et al., 2020; Breitbart et al., 2004). Additionally, clinicians can interpret from this data that parent and child benefit finding may be independent of one another and can be fostered

regardless of how other members of the family experience benefit finding. Thus, many children with advanced cancer and their parents can still navigate the positive and meaningful aspects of their lives despite having a life threatening illness.

TABLE 1: Demographic Characteristics of Mothers, Fathers, and all Children

	Mothers (n = 44)	**Fathers** (n = 24)	**Children** (n = 57)
		M (SD), range	
Age at T1 (yrs.)	42.00 (6.01), 26.6-56.6	43.80 (6.22), 30.5-54	13.3 (4.6), 5.4-23.2
Age at diagnosis (yrs.)			10.5 (5.3), 1.0-20.4
Time since diagnosis (yrs.)			3.94 (1.31), 0.89-5.98
		n (%)	
Level of completed education			
High school or grade school	10 (23.3%)	7 (29.2%)	
College, technical/trade school	21 (48.8%)	12 (50%)	
Graduate/professional degree	12 (27.9%)	5 (20.8%)	
Income			
Under-$25,000 per yr.	9 (20.5%)	5 (20.8%)	
$25,001-$50,000 per yr.	7 (15.9%)	2 (8.3%)	
$50,000-$75,000 per yr.	6 (13.6%)	5 (20.8%)	
$75,001-$100,000 per yr.	6 (13.6%)	5 (20.8%)	
$100,001-$150,000 per yr.	5 (11.3%)	3 (12.5%)	
$150,001 or more	8 (18.1%)	3 (12.5%)	
unknown	3 (6.8%)	1 (4.2%)	
Race			
White	38 (86.4%)	19 (79.2%)	48 (84.2%)
African-American	0 (0%)	1 (4.2%)	1 (1.8%)
Asian	3 (6.8%)	3 (12.5%)	4 (7%)
Other	3 (6.8%)	1 (4.2%)	4 (7%)
Native Hawaiian/Pacific Islander	0 (0%)	0 (0%)	0 (0%)
American Indian/Native Alaskan	0 (0%)	0 (0%)	0 (0%)
Ethnicity			
Non-Hispanic/Latinx	43 (97.7%)	24 (100%)	57 (100%)
Hispanic/Latinx	0 (0%)	0 (0%)	0 (0%)
Unknown	1 (2.3%)	0 (0%)	0 (0%)
Sex			
Male	0 (0%)	24 (100%)	39 (68.4%)
Female	43 (100%)	0 (0%)	18 (31.6%)
Diagnosis type			
Leukemia			17 (29.8%)
Lymphoma			5 (8.8%)
Brain tumor			10 (17.5%)
Other Solid Tumor			25 (43.9%)

Table 2: Correlations between Benefit Finding and Demographic Variables

	Child BFSC	Mother BFS	Father BFS
Child BFS	-	-	-
Mother BFS	.22	-	-
Father BFS	.21	.44	-
Child Age at T1	.26	-.09	-.18
Mother Age at T1	.37	-.01	-.29
Father Age at T1	-.12	-.06	-.17
Child Age at Diagnosis	.19	.01	-.17
Child Time Since DX	.00	-.17	-.02
Mother Education	-.26	.04	.14
Father Education	-.18	.10	.03
Mother Income	-.13	-.07	-.06
Father Income	-.36	-.11	.01

Note. N ranges from 15-44. All correlations non-significant.

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